2003

# Implementation of Occupational Therapy Services to Facilitate Independent Living for Adults with Developmental Disabilities

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# Implementation of Occupational Therapy Services to Facilitate Independent Living for Adults with Developmental Disabilities

**Scholarly Project**

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# CHAPTER 1

# INTRODUCTION

## History

Although medical knowledge of diseases and their resulting disabilities grew quickly in the 1900s, changes in the way the medical community approached individuals with disabilities was slow to follow suit and major progress was not made until the Education for all Handicapped Children Act (PL 94-142) was passed in 1975. The educational system began working in earnest with children with identified disabilities to become active participants in their surrounding environments.

Developmental disabilities are defined as not being limited to mental retardation, but include mental or physical impairments that occurred before 22 years of age, are likely to continue indefinitely, and result in substantial limitations of three or more functional areas requiring specific and lifelong extended care or support (Rehabilitation Act of 1973 Amendments). After the Rehabilitation Act of 1973 was passed, state and local governments began providing community-based housing alternatives instead of institutional placements for adults. This shift in approach presented occupational therapists with many new opportunities for practice. New theoretical frameworks and transdisciplinary teams emerged as traditional therapy practices were challenged.

This time also marked the beginning of a nationwide movement toward deinstitutionalization of the disabled. Although our current educational system is guided by a strong belief in preparing children with disabilities for full inclusion in

society, a similar commitment to inclusion opportunities for adult with disabilities is lacking. Most adults with disabilities live in nursing facilities or at home with aging parents or other family members. Primary housing in nursing facilities is a carryover of the medical model of service, prior to 1975, and implies a curative approach to service delivery. Physicians, nurses and secondary medical personnel are responsible for caring for persons with long-term supportive needs. This care requires the use of costly, licensed professionals to provide maintenance services. This is not a cost effective method of providing services for developmentally disabled persons.

The independent living movement is based on the opportunity to have an active effect on one's environment rather than being a passive recipient of the environment. The principles of choice, autonomy, and community based care are at the heart of this movement. As adults with developmental disabilities moved out of institutions and into community-based housing, occupational services in the areas of home health, community outreach, personal services management, and general application of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) were recognized as necessary for successful transition to independent living.

## Transition to Independent Living

The goals of the transitional programs are to help the clients develop the skills needed to live independently; these areas include planning and preparing meals, shopping for groceries, performing housekeeping tasks, managing medication, managing a checkbook, etc. Living independently provides numerous

opportunities for personal growth and development for this population. Most individuals with developmental disabilities have the capability to live independently provided the correct support is present, as well as the environment is conducive to learning and maximization of functional ability.

In my experience and with talking with other supportive staff for the developmentally disabled, one of the challenges faced by the support staff is that many of their clients have not had the primary responsibility for the tasks/skills needed for independent living. Selecting attainable goals and methods of achieving those goals is a difficult task. Most support programs do not conduct any evaluations of the client's ability, but occasionally they may utilizes evaluation results already noted in a client's records if they are available. If clients are not able to learn the skills needed for independent living, they continue to receive high levels of support or may transfer to an alternative living situation. The higher levels of support are, of course, more costly to provide.

Staff working with the developmentally disabled in these type of programs have no experience in activity and task analysis, little to no knowledge of the psychosocial needs of consumers, assistive technology, or the coordination of the aforementioned services. Because of this lack of assessment, individuals with developmental disabilities in these programs are not achieving their full potential secondary to inaccurate assumptions of capabilities. Both clients and staff become frustrated when expectations are too high, as well as too low.

## Assessments

Assessing the abilities of young adults with developmental disabilities is the logical first step in planning transition from living with their family of origin to living independently in the community. Numerous studies document that the results of standard tests (IQ and personality) have little relationship to actual performance of persons with special needs. Functional assessment methods that focus on the actual skills and capacities of the person are recommended (Bullis, Kosko, Waintrup, Kelley, and Isaacson, 1994). A quick screen of the client's strengths and needs will suggest specific areas to assess. Knowing the client's vision, hearing, cognitive level, posture, communication, and ambulation status will indicate which areas should be concentrated on.

## Implementation of OT

After examination of various transitional programs, it is believed that implementation of occupational therapy services will greatly improve the quality of care provided for individuals with developmental disabilities served through these programs. Currently, in transitional programs, clients are not achieving their full potential secondary to inaccurate assumptions of capabilities. When clients receive assessments by an occupational therapist to help determine their capacity, their present abilities plus the power to develop new physical or cognitive skills, realistic and appropriate goals can accurately be determined to match their functional level. The occupational therapist will be responsible for assessing client abilities and current cognitive level, creating an environment that would facilitate

client success, creating the intervention plan for the client, and training support staff to follow through with the environmental structuring and interventions.

Tasks that the individual has difficulty with can be broken down into individual steps (a task analysis), and training the support staff to teach clients the incremental steps (or protocols) will make skill acquisition more manageable. This would result in more effective learning by the client, enabling them to safely perform activities of daily living without the need of supervision. This may decrease the support needed by clients, and would thus lower the costs incurred by community living agencies.

Occupational therapists are skilled and extensively trained in the areas of physical and psychosocial disabilities. Occupational therapists are therefore experts in evaluating and treating the "whole person." Occupational therapists are also qualified in adapting the environment of an individual with developmental disabilities to provide the consumer with the opportunity for mastery of his/her environment. The individuals participating in these transitional programs are required to increasingly function independently in a variety of home living tasks. Occupational therapists are skilled in function-based therapy, treatment, and modifications. They are professionals that will see the consumer holistically and are trained to evaluate every aspect of the person with whom they work.

It is this author's belief that if clients were to receive assessments by an occupational therapist to help determine their cognitive level, realistic and appropriate goals could be determined to match the functional level. The maximum level of independence could be more accurately predicted and achieved.

# CHAPTER 2

# REVIEW OF LITERATURE

## History of Services for the Developmentally Disabled

In the early 1900s, many persons who appeared less than perfect in any way were classified as "defective" by both the medical community and society as a whole. This classification was used to describe persons who were paralyzed, deaf, blind, mentally retarded, poor, or unemployed. (Wolfensberger, 1975) In 1912, W.E. Fernald published an article in the Journal of Psycho-Asthetics titled, "The Burden of Feeble-Mindedness." The article stated "the social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are parasitic, predatory class, never capable of self-support or managing their own affairs." (Fernald, 1912) Even into the 1920s, Public Health Service combined "criminals, defectives, and delinquents" for reporting purposes (Wolfensberger, 1975). In this era the medical profession began its pursuit for knowledge of disease and its' causes. The medical community approached disabilities in terms of how to "fix" the problem.

Although medical knowledge of diseases and their resulting disabilities grew quickly in the 1900s, changes in the way the medical community approached individuals with disabilities was slow to follow suit and major progress was not made until the Education for all Handicapped Children Act (PL 94-142) was passed in 1975. The educational system began working with children with disabilities to become active participants in their surrounding environments. In 1978, a legislative definition of developmental disabilities was outlined in the

Rehabilitation Act of 1973 amendments. It states that developmental disabilities are not limited to mental retardation, but include mental or physical impairments that occurred before 22 years of age, are likely to continue indefinitely, and result in substantial limitations of three or more functional areas requiring specific and lifelong extended care or support (Rehabilitation Act of 1973 Amendments). State and local government began providing community-based housing alternatives to institutional placements for adults. This shift in approach presented occupational therapists with many new opportunities for practice. New theoretical frameworks and transdisciplinary teams emerged as traditional therapy practices were challenged. This time also marked the beginning of a nationwide movement toward deinstitutionalization of the disabled. The Americans with Disabilities Act of 1990 (ADA), addressed physical issues of access and architectural obstacles. This legislation literally opened the doors to full participation in society for disabled persons. Today, environmental barriers, not individuals with disabilities, are viewed as needing to be “fixed”.

The number of adults diagnosed with developmental disabilities continues to grow secondary to decreased mortality rates and improved health care. Although our educational system is guided by a strong belief in preparing children with disabilities for full inclusion in society, a similar commitment to inclusion opportunities for adult with disabilities is lacking. Most adults with disabilities live in nursing facilities or at home with aging parents or other family members . Primary housing in nursing facilities is a carryover of the medical model of service, prior to 1975, and implies a curative approach to service delivery.

Physicians, nurses and secondary medical personnel are responsible for caring for persons with long-term supportive needs. This care requires the use of costly, licensed professionals to provide maintenance services. This is not a cost effective method of providing services for developmentally disabled persons. (Richard, & Nelson, 2002)

## Current Trends in Services for the Developmentally Disabled

The independent living movement is based on the opportunity to have an active effect on one's environment rather than being a passive recipient of the environment. The principles of choice, autonomy, and community based care are at the heart of this movement. As adults with developmental disabilities moved out of institutions and into community based housing, occupational services in the areas of home health, community outreach, personal services management, and general application of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) are needed for successful transition to independent living.

Although some independent living supporters believe complete deinstitutionalization is essential, others view institutions as one option in a continuum of care. Institutions may be appropriate for some persons with disabilities but it is not the best fit for all persons. In 1999, the case of Olmstead v. L.C. and E.W., the Supreme Court ruled that it is a violation of the Americans with Disabilities Act when persons are kept in institutions, nursing homes, and mental health facilities when they could receive community based treatment and live at home or elsewhere in the community. This case involved two women with mental illness and mental retardation who were unnecessarily institutionalized in a

Georgia State psychiatric hospital while they waited for years for community placement. In its ruling, the Supreme Court established two criteria to determine whether a placement is the most integrated setting appropriate for each person. The first criterion requires that a "reasonable" evaluation of the person's community readiness be performed by the state's treating professionals who are knowledgeable about available community supports and services. In addition, a person cannot be determined "not ready" for community placement just because community services are not currently available. The second criterion for community placement is that the person being recommended must accept the transfer (Olmstead v. L.C., 1999). Following this ruling, most states were caught unprepared for the change in housing options for persons with disabilities. Choices now range from group homes to foster care families to supervised apartment living, in-home family services, and respite care.

The reimbursement system for care of adults with developmental disabilities is filled with remnants of earlier models. Medicare is designed for hospital and rehabilitative services which may restrict access to community based services. Long-term care needs are paid through the Medicaid system, which was created by Title XIX of the Social Security Act to provide health care services to persons who are financially needy (Anderson, 1993), suggesting that persons with lifelong supportive needs must remain at the poverty level to receive the services they require for daily living. These systems are counter-productive to the vision that all persons can contribute to and participate in society.

Adults with developmental disabilities experience the same health care needs as members of the typical population. Conditions such as orthopedic impairments, cardiovascular problems, hypertension, arthritis and cancer appear to occur among persons with developmental disabilities in patterns similar to how they appear among the general population (Anderson, 1993; Kapell, Nightingale, Rodriquez, Lee, Zigman, & Shupf, 1998; Ridenour, & Norton, 1995). Adults with developmental disabilities also experience cognitive and psychiatric disorders, including Alzheimer's disease, dementia, depression, and bipolar disorders (Cherry, Matson, & Paclawskyj, 1997; Hotaling, 1998; Wisniewski, Silverman, & Wegiel, 1994). The recent shift in service delivery and care of adults with developmental disabilities results in health care for this population being provided by acute and rehab hospitals, community clinic settings, and home health care.

## Occupational Therapy Services for the Developmentally Disabled

The occupational therapist working in a health care setting or in home health care will most likely have the opportunity to evaluate and offer intervention services to an adult with developmental disabilities. The process a therapist uses to evaluate a client with developmental disabilities is dependent on several factors. These include the needs and interests of the client, the priorities expressed by the family and supportive services, if a referring medical diagnosis is present, and in part the frame of reference used by the therapist and facility. To begin an evaluation, the therapist should interview the client to the greatest extent possible, along with the client's family and staff members. This initial interview will guide the occupational therapist on how to proceed. In some cases, the client may be

nonverbal or use an assistive device to communicate. It is important to identify the client's communication patterns before beginning the interview. It has been found that when working with clients who are nonverbal or who have severe impairments and are unable to communicate their wants, needs, and preferences, a different approach needs to be taken in order to determine the client's previous level of functioning, preferences, and interests. Interviewing family members, caregivers, and guardians can give a therapist important background information. The therapist must be aware that the staff or family members may at times be sharing their own goals, interests, desires, and dreams rather than those of the client (Reisman, & Hanschu, 1992).

Assessing the abilities of young adults with developmental disabilities is the logical first step in planning to help them transition from living with their family of origin to living independently in the community. Numerous studies document that the results of standard tests (IQ and personality) have little relationship to actual performance of persons with special needs. Functional assessment methods that focus on the actual skills and capacities of the person are recommended (Bullis, et al., 1994). A quick screen of the client's strengths and needs will suggest specific areas to assess. Knowing the client's vision, hearing, cognitive level, posture, communication, and ambulation status will suggest which areas should be concentrated on. The therapist also needs to listen for evidence of changing functional status. There is a high incidence of associated disorders among persons with developmental disabilities. Persons with Down Syndrome, for example, are at increased risk for early onset of Alzheimer's disease, deafness,

eye disease, congenital heart disease, and psychiatric disorders (Martin, 1997). Often caregivers do not identify changes in the client's performance unless the changes are dramatic and occur suddenly.

Several occupational therapists have developed assessment tools to help identify a client's capacity. A number of assessments tools that are standardized to persons with developmental disabilities are available to therapists (Asher, 1996). Often, occupational therapists will need to adapt the evaluation process traditionally used in order to address the client's specific needs and capabilities without compromising the assessment tool (i.e. recognizing standardization procedures, noting prompts and cues when required for the client to complete the task, etc.). According to Claudia Allen, capacity includes present abilities plus the power to receive and develop new physical and cognitive abilities (David, & Riley, 1989). Two assessments, Allen Cognitive Level Test and the Routine Task Inventory, designed by Allen and associates are summarized below.

The Allen Cognitive Level Test (ACL) is a quick screening instrument that is used in the initial evaluation of client's functional abilities and deficits. The ACL screening involves three different leather stitches. The test evaluates the client's ability to follow verbal directions with demonstrations, to solve problems involving a progressively more elaborate task, and to learn through demonstration and trial and error (McAnanama, Rogisin-Rose, Scott, Joffe, & Kelner, 1999). The determination of cognitive level is based on the complexity of the stitch that the client is able to imitate and observations of the client's behavior while doing this task (David & Riley, 1989). The ACL does not rely on the client's verbal abilities,

and conversely, high verbal skills cannot mask a client's functional deficit (Allen, Earhart, & Blue, 1992). The resulting information, despite the presence or absence of verbal input, indicates their cognitive functioning level and generates practical recommendations regarding the client's learning capacity, provides guidelines for designing achievable goals, and indicates the nature and level of assistance required for the client to complete activities of daily living (Sweetingham, 1996). Currently, the ACLS is not standardized for the developmentally disabled population. Many occupational therapists have recognized it's potential applicability to this population and research is currently being conducted. Herge and Loving (2002), both MOTS, are actively pursuing the use of Claudia Allen's Cognitive Disability Model with the developmentally disabled population. They have presented a workshop entitled "Piloting the Application of the Cognitive Disability Model in Adult Day Programs for the Developmentally Disabled" at several OT – Innovation: Allen Symposiums around the country. Initial research is very promising, but further research is necessary to determine the validity and reliability with this population.

The Routine Task Inventory - 2 (RTI-2) is often used in conjunction with the ACL. It utilizes common scenarios and tasks to further illustrate the cognitive and functional abilities of a client. The RTI-2 can be used to formulate goals, assist in determining which tasks need to be analyzed to facilitate learning, to design a home program, and assist in matching activities to current level of function. The RTI-2 is completed by self-report, caregiver report and/or observation by a skilled occupational therapist.

The RTI-2 evaluates self-awareness, situational awareness, social roles and occupational roles. Self-awareness includes the activities one does to keep one's body clean, safe, healthy, comfortable and attractive. The universal nature of these activities makes it possible to list the steps required to complete each task. Tasks included are grooming, dressing, exercising, eating, and taking medication. Situational awareness refers to the ability to understand situations of daily living encountered at home or in the community. This includes housekeeping tasks, preparing/obtaining food, tasks related to money use, shopping, doing laundry, traveling, telephoning and how a client adapts to a change in their usual routine. Social role abilities are needed to interact with other people, and consist of the ability to communicate, follow directions, and cooperate with others. Occupational Role tasks relate to performing a major role, such as going to work or to school. This includes following a schedule and the ramifications of changing that schedule. Planning and doing spare time activities, following safety precautions and responding to emergencies are some of the other skills that are included in this area. (Allen, et al., 1992)

The ACL and RTI-2 are used to determine the cognitive abilities of a client, with Level 1 indicating severe disabilities requiring custodial care, and Level 6 indicating an absence of disability. At Level 2, the client is mobile but requires total assistance for all self-care activities. At Level 3, the client needs constant supervision and moderate assistance. At Level 4, the client needs minimal assistance with physical routine tasks, such as personal care, although their clothing and appearance may seem "odd". Clients at Level 4 need assistance

in their performance of tasks such as shopping, cooking, budgeting, and medication compliance. Because clients with a Level 4 cognitive ability cannot adapt to minor environmental changes, following a set routine is vital. At Level 5, a client's ability to adjust to changing steps in a task is observable. These persons can live independently but have limited capacity for planning and, as such, benefit from periodic support (McAnanama, et al., 1999).

The ACL and RTI-2 have been successfully used with clients of varying diagnoses, such geriatrics, schizophrenia, bipolar disorder, other affective and personality disorders. Although no evidence of documented application of Allen's theory to the developmentally disabled population was discovered, David and Riley (1989), suggested that the ACL was "potentially useful for screening cognitive dysfunction associated with organicity" (pp. 493-7). This author consulted several professionals familiar with Allen theory and together they postulated that the assessments would be applicable with the DD population. The outcomes of the RTI-2 and the ACL would be instrumental in assessing a young adult's current cognitive abilities and predicting the potential level of function achievable over time with proper structuring of environment and task.

Several other assessments have been found to be useful with this population. The Sensory Integration Inventory – Revised (SIIR) is useful for screening clients with developmental disabilities for possible sensory integration (SI) dysfunction. The therapist interviews a caregiver who is familiar with the client or completes the inventory if he or she knows the client well. This tool is not meant to diagnose SI dysfunction, but rather to help identify possible patterns of

dysfunction. Interpreting the results relies on the therapist's knowledge and understanding of SI dysfunction, which may lead to further assessment (Reisman, & Hanschu, 1992). Another assessment which may be utilized is the Kitchen Task Assessment which was developed as a practical, objective measure of cognitive function demonstrated in a common task (such as making cooked pudding). Originally, the sample population was adults diagnosed with Alzheimer's disease; however, it has been hypothesized that this tool would be useful for clients functioning at higher levels (i.e. borderline mental retardation or learning disability). This tool can help the therapist determine the level of assistance the client may require to perform tasks safely, which can be helpful when making recommendations for supervision in a home environment. An environment assessment can be developed in order to complete a home environment checklist. These checklists typically include an evaluation of the entryway, bedroom, bathroom, kitchen, and other living areas (Pedretti, 1996).

## Summary

Intervention planning relies on several factors, these include the needs and interests of the client, family, and caregivers, environmental considerations, agency priorities, and funding priorities. Intervention planning also needs to take into account the client's ability to process information, learn new skills, and attend to therapy, as well as the caregiver's ability and willingness to provide follow-up care. As with any client or patient, it is important for the therapist to develop intervention plans that are meaningful to the client with developmental disabilities and the family or caregivers. Clients with sever impairment or who are nonverbal

pose unique challenges. Information can be obtained from interviewing primary caregivers, clinically observing the client in his or her own environment, and reviewing the client's history. Active participation of the client, family, caregiver, and service providers in an appropriate team process helps ensure that the intervention recommendations meet the client's needs. Goals and objectives should be measurable and achievable, consider the client's previous level of independence, and take into account the cognitive disability.

Assessment findings regarding the client's cognitive functioning and specific adaptations or prompts and cues need to be recorded and communicated with other team members to ensure the client receives the best possible care. It is often the occupational therapist's role to share information with other team members regarding the developmental disability's impact on the client's ability to participate in the intervention process. It is important for therapists to consider the client's cognitive limitations when making environmental and intervention recommendations. Intervention plans should account for the need for many performance repetitions in multiple environments to ensure learning and generalization. Clients with developmental disabilities may have difficulty processing information rapidly. The intervention plan should also include training family and supportive staff so they will be consistent in presenting the tasks and environmental recommendations.

The occupational therapist must consider particular caregiver's strengths and needs when establishing an intervention plan for the client. The therapist must also seriously consider the usefulness of the intervention strategies that cannot be

delivered properly or consistently. Support staff may require additional training in specific techniques or staff members may rotate through a residential setting with the client receiving care from a variety of different people all with their own techniques.

Occupational therapists are in a unique position to help make independent living within the community as successful as possible for adults with developmental disabilities. With training in cognitive and physical dysfunction, environmental adaptations, and task and activity analysis, occupational therapists can evaluate and address the physical, self-care, vocational and leisure needs of adults with developmental disabilities living in the community. Carefully evaluating the client's strengths, needs, and environmental factors will help therapists establish a intervention plan that will enhance the client's ability to function independently and improve his or her quality of life in the community.

# CHAPTER 3

# METHODOLOGY

The author of this scholarly project has demonstrated an extensive and invested interest in services offered the developmentally disabled population. In 2000, the author began working with the developmentally disabled population in the Grand Forks area. Through working with the transitional and independent living programs at Support Systems, Inc. (SSI), she noted many areas which could be greatly enhanced through accurate assessment of client capabilities and structuring of the client's environment to facilitate success.

As a result of observation, the author chose to complete a program plan for implementation of occupational therapy services within SSI's Transition and Individual Supportive Living Arrangements (ISLA) programs for her Organization and Administration course in the occupational therapy program at the University of North Dakota. An literature review and a survey of current support staff was completed for this project. Results of the survey indicated many areas of concern for support staff who work with the clients on a day to day basis. During a given month as many as twenty staff members may work with a single client, therefore there is a considerable variation of expectations and methods utilized with the client simply because of the different personalities of staff members involved.

Another concern expressed was that a large percentage of the support staff are college students who work with the clients for only a year or two while attending school. This can be difficult for the clients as they build relationships with staff who do not remain as long-term support systems for them. It is an

advantage, however, to have staff who are of similar age and are peers of the clientele. This provides the clients with the opportunity to spend time with others their own age, and increases the participation in age appropriate activities. Forty percent of the support staff surveyed felt that clients are being challenged to meet their full potential. They justify their responses by stating that support staff challenge clients to do their best, and that the clients are continually learning new skills and increasing their independence. Sixty percent of the staff members indicated concerns about the amount of challenge provided for the clients.

Several staff members expressed concerns over inconsistencies in routine and felt that that a daily routine needs to be set and followed with each client. Others mentioned that there was a lack of communication regarding skills gained and new goals. This would obviously limit the progress made by a client. Staff also addressed the appropriateness of goals. Several staff members commented that there was a lack of information regarding goals, goal progress, and when goals had been met. Several indicted that it was difficult to teach new tasks to the clients. Many reported becoming easily frustrated with the clients' attempt to complete tasks independently, when the task could be accomplished much quicker by the staff member alone. A need for staff centered services: posting goals, noting progress, dealing with negative behaviors and assistance in working with some parents was identified through this survey.

Results of this survey, discussion with Support Systems administration, and a review of the literature indicated that occupational therapy services could enhance the quality of services provided to the clients in the Transition and ISLA

Programs. The program plan developed included assessment of the client's cognitive functioning level, development of appropriate goals, establishing activity protocols, staff in-service training, and continual monitoring of the program's efficiency. These steps were developed to meet the needs of the clients and providers of the ISLA and Transition Programs.

This past semester a business plan for implementation of occupational therapy services for SSI was completed by the author for a Masters level Leadership and Management course in the occupational therapy program (Richard, 2003). This business plan consisted of outlining implementation of occupational therapy services into SSI. This project included defining ownership, description of the business, market information, strengths and weaknesses of the program, defining competitors, a marketing strategy, management, and financial budgeting for monthly expenditures, as well as projected startup and a yearly budget. This project explored the various business aspects of implementation. This research was valuable when determining the feasibility of implementing occupational therapy services. The research indicated that past trends have shown the number of individuals in the transition and ISLA programs have been consistently increasing over the past 5 years as the programs become more established in the community. This trend is projected to continue in the future as well. Based on funding through Medicare, Medicaid, private insurance, and state funds allotted for the developmentally disabled, funding for implementation of occupational therapy services was found to be a financially stable endeavor for SSI.

Through other coursework in the Masters program, the author has explored other areas of expansion of occupational therapy services to this population. A research paper on assistive technology and the developmentally disabled was written for an Assistive Technology course. Individuals with developmental disabilities (DD) often have difficulty performing day to day activities without assistance, whether it is from other people or assistive technology. Assistive technology can easily be applied to this population to increase independence with nearly every aspect of their lives. The goal of the paper was to outline several common problem areas for individuals with DD and potential assistive technology which can be applied to aid independence.

The purpose of this scholarly project was to develop a protocol to address the needs of an adult population with developmental disabilities in order to facilitate independent living in the community. Based on research completed for a series of projects a need for this type of programming has been identified. Based literature from a previous study, it is this author's belief that if clients were to receive assessments by an occupational therapist to help determine their capacity, their present abilities plus the power to develop new physical or cognitive skills, realistic and appropriate goals could be determined to match the functional level. The maximum level of independence could be more accurately predicted and achieved by structuring the environment and activities to meet occupational expectations of independent living. This need was addressed through the use of materials based on Claudia Allen's Cognitive Level Test (McAnanama, et al., 1999) and the development of protocols for program implementation.

Activities for this project included a literature review in the area of programming for adults with developmental disabilities and of utilization of Claudia Allen's Cognitive Level Test with this population. Based on the literature, a protocol was established which will allow an occupational therapist to break tasks down into individual steps (a task analysis), and then train staff to teach clients the incremental steps in order to make skill acquisition more manageable. Future research is needed to determine the effectiveness of the protocol.

# CHAPTER 4

# PRODUCTS

# Occupational Therapy Services for the Developmentally Disabled Manual

## Table of Contents

**Protocol for Providing Occupational Therapy Services**

1. Interview and History
    - Family completion of the Client History Form (p.5)
    - Interview with client and family
    - Identification and write up of family concerns and personal objectives (p. 7)
2. Administration of the Allen's Cognitive Level Assessment (p. 9)
    - Determination of the client's functional level
3. Other assessments (as needed)
    - Routine Task Inventory 2 (p. 21)
    - Kitchen Task Assessment (p. 22)
    - Environmental Assessments (p. 22)
4. Establish goals and create an intervention plan (p. 23)
    - Identify tasks which the client requires assistance to complete successfully
5. Task Analysis Protocol (p. 28)
    - Break tasks into incremental steps in order to make skill acquisition more manageable
6. Staff Training Protocol (p. 34)
    - Handout to support staff on ACL levels (p. 35)
7. Teach client task and modify environment as necessary to facilitate independence
8. Monitor performance and modify as necessary

## Client History

**Name:** _____

**Age:** _____ **Date of Birth:** _____

**Parents' Names:** _____

**Address:** _____

**Phone Number:** _____

**Medical Information**

**Physician:** _____

**Phone Number:** _____

**Allergies:** _____

**Medications:** _____

_____

**Diagnosis:** _____

_____

_____

**Client History**

**Where and with whom has the client lived within the past 10 years?** _____

_____

_____

**Siblings and their ages:** _____

_____

**Schooling?** _____

**Has the client held a job for any substantial period of time? If so, where?**

**What activities does the client complete independently at home?**

**Does the client complete self-cares independently or does he or she require assistance?**

**Does the client prepare any meals independently?**

**Who is responsible for medications?**

**Does the client demonstrate any behaviors which should be noted?**

**What concerns do you have?**

**Signature** **date**

## Family Concerns

**Concern 1:** _____

_____

_____

**Plan to address concern 1:** _____

_____

_____

**Concern 2:** _____

_____

_____

**Plan to address concern 2:** _____

_____

_____

**Concern 3:** _____

_____

_____

**Plan to address concern 3:** _____

_____

_____

_____ _____

**Client Signature** **date**

_____ _____

**Family Member Signature** **date**

_____ _____

**OT Signature** **date**

**Personal Objectives (as expressed by the client and/or family members)**

**Objective 1:** _____

_____

_____

**Objective 2:** _____

_____

_____

**Objective 3:** _____

_____

_____

_____ _____

**Client Signature** **date**

_____ _____

**Family Member Signature** **date**

_____ _____

**OT Signature** **date**

# Allen Cognitive Level Screen 2000

This document is taken verbatim from the Allen Conferences, Inc. website at www.allen-cognitive-levels.com/acls.htm.

This is the fourth revision of the original screening tool **(**Allen**,** 1985; Earhart & Allen**,** 1990, Earhart & Allen**,** 1996). This revision simplifies the scoring criteria by eliminating odd-numbered scores. The even numbers are consistent with the modes assessed by the Allen Battery. The directions have been elaborated to clarify interventions in the screening process. Two versions of the screening tool exist, a regular size (called the ACLS) and a larger version (called the LACLS).

## The Allen Cognitive Level Screen and the Allen Battery

The Allen Cognitive Level Screen (ACLS) is part of a body of assessment tools and references that comprise the Allen Battery. The screening tools are designed to provide an initial estimate of cognitive function. The score from the screen must be validated by further observations of performance.

The anticipated discharge environment determines the selection of further observations of performance. When the anticipated discharge setting is a stable home environment or an institution, activities of daily living (ADLs) can form the basis for further observation. ADLs use procedural memories to follow habitual routines in an environment that is not changing. The most common ADLs are analyzed in the Routine Task Inventory (chapter 7) in *Occupational Therapy Treatment Goals for the Physically and Cognitively Disabled (*Allen, Earhart, and Blue, 1992) and in the methods and safety sections of *Understanding the Cognitive Performance Modes* (Allen, Blue, & Earhart, 1995).

When the anticipated discharge environment is the community or other changing environment, working memory must be assessed. Working memory processes new information in order to adapt to a changing environment. The most effective method of assessing working memory is with the craft projects in the Allen Battery. The *Allen Diagnostic Module Instruction Manual* (ADMIM) (Earhart, Allen, & Blue, 1993) provides the observations of performance for each craft project in the Battery.

The person's best ability to function takes place in the least restrictive environment. When the environment corresponds to the person's Allen Cognitive Level, the person can function at his/her best ability to function. Human and non-human environments can be redesigned to compensate for limitations and encourage the use of remaining abilities (*Structures of the Cognitive Performance Modes*, Allen & Bertrand, 1999). Caregiver education is a major part of the use of the ACL so caregivers can increase the safety of self and others. The ACLS initiates the process

of advising people with a cognitive disability and their caregivers about living with the condition. When changes in ability to function occur, cases are re-opened to design a revised functional maintenance plan.

The ACLS shares the advantages and disadvantages of most screening tools. The ACLS is quick and easy to administer. Some people are frightened by tests and may refuse to cooperate. Accept the refusal graciously and try to elicit the person's cooperation in performing an appropriate Allen Battery activity.

The ACLS screens only ACL Modes 3.0 through 5.8. At Levels 1 and 2 people do not work with objects, and Level 6 is concerned with attention to symbolic cues. The ACLS is designed to access the middle of the ACL range where the most important questions about ability to function occur.

# The ACLS Kit Includes:

3-3/4" x 4-3/4" punched leather rectangle, 1 Instruction Manual, 1 blunt sewing needle, 1 hank of waxed linen thread, 2 Perma-Lok lacing needles, and 1 hank of leather lacing

# Set up the ACLS

The kit is prepared ahead of time using the assembly instructions described below. Refer to the diagram A (same as original).

1. Cut a 15" length of waxed linen thread and tie a large knot in one end. Thread the other end through the sewing needle. Holding the leather rectangle with the shiny side towards you and the long side horizontal, start on the bottom of the leather about one hole to the left of the curved portion. Push the needle from back to front and come up through the next clockwise hole of the leather. Complete three running (sewing) stitches, working from left to right (clockwise). Three stitches means the needle should have gone through seven holes. The thread should exit to the front of the leather when ready to use.
2. Cut two 30" lengths of leather lacing. Prepare one end of each lacing by cutting it at a sixty degree angle. You will notice that the brass needle has screw threads inside one end. Insert the prepared end of the lacing into the needle and "screw" the needle onto the lacing. The lacing should be attached to the needle with a bond strong enough to resist a gentle tug. Prepare the other lacing and needle in the same manner.
3. Set up the whipstitch: Hold the leather rectangle with the shiny side towards you and with the running stitch on the bottom. The whipstitch starts at the two o'clock position (in the middle of the curve). The end of the lacing may

be secured under the first stitch or left hanging free. Keep lacing flat (no twists). Pull each stitch TIGHT. After first stitch, complete three or four stitches, working left to right (clockwise). The last whipstitch should be on the straight (as opposed to the curved) portion of the leather.

4. Set up the single cordovan stitch (Refer to the diagram B): Hold the leather rectangle with the shiny side towards you and with the running stitch on the bottom. Start the single cordovan stitch at the eleven o'clock position. Starting from the front of the leather rectangle, thread the needle and lacing through the hole. The end of the lacing may be secured under the first stitch or left hanging free. Come over the leather edge and go through the next hole, as if you were making another whipstitch. Do not tighten the stitch but leave a small loop about ½ inch in diameter. Go through the loop from front to back with the needle and lacing leaving another small loop about ½ inch in diameter. Be sure there are no twists in the lacing. Tighten the first loop by pulling the lacing tight from the rear of the leather. Tighten the second loop by pulling (tight) the lacing in the direction of the next hole to be used. Complete three more single cordovan stitches. Be sure the last stitch is on the straight (as opposed to the curved) portion of the leather. Be sure that the tension on all stitches is uniform, as tension of the stitch is one of the scoring measures.
5. Check to ensure that needles and thread or lacing go through all holes easily. If necessary, the holes may be enlarged using an awl or a ballpoint pen.
6. If desired, a pocket (made from another piece of leather or an index card) can be affixed to the back of the leather to store unused lacings while screening. Storage is recommended when persons screened demonstrate confusion about which hole to go through next while doing the running stitch. The difficulty in finding the next hole may reflect a focal perceptual deficit in imagining a line. Stitch deficits may be seen in diagnostic groups such as dementia, CVA, or traumatic brain injury. Dangling lacings further confuse these persons. When diagnosis is uncertain, leave all lacings out of the storage pocket to assist in detection of such focal deficits.

# Initial Preparation to Administer the Screen:

The person administering the screen is referred to as the *administrator*; the person being screened is referred to as the *person.* Prior to administering the ACLS for the first time, the administrator should:

Practice holding the leather so the person can clearly see the demonstration. An administrator should be able to do all three stitches while standing or sitting on the person's left. Practice doing stitches while holding the leather out to the right (where it would be in front of person).

Memorize the verbal directions and then practice combining the demonstration and verbal directions. It is not necessary to be able to recite the directions from memory, but an administrator should have a clear idea of the directions, the words to say, and the next steps in the screen. The verbal directions should not deviate markedly from

the instruction book, nor be elaborated upon. It is recommended that the directions for administering the screen be on your lap to refer to if one of those "total losses of memory" occurs.

- Select a location for the screening that offers the best light and the fewest distractions.
- Construct a brief interview that can be used to get to know the person before administration of the screen. If rapport can be established with the person, it less likely to get a refusal to try the screen.
- Always start with the running stitch. Busy administrators may be tempted to skip the running stitch when person is coherent during the interview. The time saved is rarely worth what is lost. If the person does the running stitches easily, he/she gains confidence to try the harder stitches. If the person complains of visual impairments later in the screen, it may be possible to rule out bad vision based on how the running stitch was done.
- Be prepared to stop the screen when an error is made and not corrected. Score the highest level achieved. An exception to stopping the screen should be made when a focal deficit in imagining a line is suspected in the running stitch. In this case, continue on to the whipstitch.
- It is a good practice to have a LACLS and an extra ACLS handy on the floor by your left hand. With this preparation, when the person says, "I can’t see the holes" the LACLS can be substituted or if a needle comes off the leather lacing, the other ACLS can be substituted.

# Maintenance of the Screens

Over time the leather lacing becomes worn by twisting and dirt can obscure the difference between the smooth and rough sides. The linen thread may split or fray. Replace the lacing and thread when this happens.

Pieces of leather lacing which break off inside the Perma-Lok needles can be removed by burning with a match.

A finish can be applied to the leather if desired to protect it from becoming dirty.

The kit can be disinfected with alcohol (or whatever solution your facility uses).

# General Notes

Start with the small ACLS and switch to the LACLS to compensate for impairments such as vision problems, hand tremors, or hemiplegia. If the switch to the larger version occurs, avoid giving three demonstrations. A third demonstration is acceptable while administering the running stitch, but a third demonstration should be avoided in the whipstitch.

Check the person's vision by asking **"Can you see the holes?**" When beginning the whipstitch, check vision again to see if the person can see the smooth/dark versus rough/light sides of the lacing. If they cannot see this difference, switch to the LACLS. Not being able to see is a frequent excuse for an inability to do a stitch.

It is permitted to hold the leather for persons who have the use of only one hand. Be careful not to rotate the leather to show the person errors on the back. Tell the person to turn it as they want. If the person is using the non-dominant hand, the person may be slow. Reassure the person that it is not a timed screen and the person can take as long as the person needs.

If you are left-handed, you must administer the screen with your right hand. If the person with a possible cognitive disability is left-handed, the screen is still administered with the right hand.

Throughout the screen, you may offer words of encouragement: **"Take your time; you are doing fine; I appreciate your efforts".** Be careful not to give cues on how to do the stitch.

### Preparation for Administering the ACLS

Before administering the ACLS, verify that ACLS only has three running stitches (six holes) which exit on the smooth side, four whipstitches, and four single cordovan stitches. Remove any excess stitches.

Begin by establishing rapport with the person to be screened. A good way to develop rapport is with an interview that establishes the person's functional history. One of the best questions is to ask the person to describe a recent typical day. Show the leather lacing samples to the person and explain why you are doing the assessment.

**"Have you ever done anything like this before?"**

If yes, find out how much and how long ago. On occasion, a person may be encountered who has done a lot of lacing. The ACLS may not be testing new problem solving abilities, and the ACLS score may be higher than the person's ability to function.

**"Can you see the holes?"** If no, change to the LACLS.

## Running Stitch:

**"I am interested in seeing how you follow directions and concentrate. I will show you how to do a stitch now, so watch carefully what I do."** The administrator holds the leather with running stitch at top edge so that it is facing both the administrator and the person. Hold the leather in front of the person so that

both sides of the leather can be seen. **"Take the needle and push it down through the next hole and pull the thread through the hole. Push the needle up through the next hole. Pull the needle through the hole and tighten it. Don't skip any holes. Now you do it."**

Hand the leather and the needle to the person. These verbal directions and demonstrations can be repeated once if the person cannot complete the stitch on the first attempt. If the person stops before going through six holes, urge them to continue. If the person cannot complete the stitch after the second demonstration, thank them for participating and end the screening.

If the person has trouble seeing the holes, try to anticipate the need for changing to the LACLS before giving the second demonstration. If you have to change to the LACLS, a third demonstration may be given.

If errors are corrected or no errors are made, proceed to demonstrate the whipstitch.

# Interventions for errors – Running Stitch

| | | |
|---|---|---|
| 1. **"Is yours like mine?"** "**No."** Go to step 3. If spontaneous fixing occurs, no further intervention may be required. | 3. **"How is it different?"** Points to or names error. Go to step 5. Keep quiet if the person starts to fix it spontaneously. | 5. **"Can you fix it?"** Attempts removing error and starting ov |
| 2. "**Yes**" or no response to question of **"Is yours like mine?" "You have a mistake. Can you find it? Show me where it is."** | 4. Does not identify error. **"Your mistake is right here,"** while pointing to the error. **"I want you to make yours look just like mine."** | 6. No attempt or an ineffective fix. **"Would you like me to sl again?"** Take out the error an demonstration over. Repeat th demonstration one time., If yo impairments (hand or vision) explain the person's difficultie the LACLS now. |

# Whipstitch:

If the person is able to complete the running stitch, the administrator goes on to the whipstitch. The whipstitch verbal directions and demonstration can be repeated once if the person cannot complete the stitch on the first attempt.

**"See how the leather lacing has a dark, smooth side and a light, rough side."** Check the person's vision by looking at the person's face and obtaining an acknowledgment to be sure that the person sees the two sides of the lacing**.** If they

cannot see the two sides, switch to the LACLS. **"Always keep the smooth, dark side up as you do each stitch, being careful not to twist the lacing. Now I will show you another stitch. Watch me carefully. Take the lacing and bring it around to the front, over the edge of the leather. Push the needle through the hole and tighten it. Be sure the lacing isn't twisted. Don't skip any holes. Now you do 3 stitches."** If the person stops after one stitch ask the person to do at least 3 stitches by asking, **"Can you do two more?"**

Two errors that are part of the rating criteria do not always occur: the cross in the back and twists in the lacing. When the problems do not occur, the errors should be introduced. If, however, the cross and/or twist do occur spontaneously, it is not necessary to repeat this/these problems. The instructions for introducing either of these problems are as follows: **"I'm going to make a mistake to see if you can correct it."** The administrator takes the ACLS and holds it to the left side to shield it from the person. On the backside of the ACLS, push the needle through the loop, trapping the lacing underneath the loop. This forms a cross in back of the ACLS. Hand the ACLS back to the person. **"Can you show me my mistake?" "Can you fix it?"**

If the person can point out and correct the cross error, demonstrate the twist. The administrator takes the ACLS and introduces a twist in the last stitch. Make the twist clearly visible. Hand the ACLS back to the person.**"I have made another mistake." "Can you show me my mistake?" "Can you fix it?"**

If the person starts to correct the twist by taking the stitch out, stop the person. Ask **"Can you do it without taking the lacing out of the hole?"**

# Interventions for Errors - Whipstitch

As soon as a mistake is made, prompt to determine if the person can correct the error. The person should not continue to do more stitches with an error in a previous stitch.

The following prompts and interventions can be used:

| | | |
|---|---|---|
| 1. **"Is yours like mine?"** "**No.**" Go to step 3. If spontaneous fixing occurs, no further intervention may be required. | 3. **"How is it different?"** Points to or names error. Go to step 5. Keep quiet if the person starts to fix it spontaneously. | 5. **"Can you fix it?"** At by removing error and s |
| 2. "**Yes**" or no response to question of **"Is yours like** | 4. Does not identify error. **"Your** | 6. No attempt or an inef attempt to fix. **"Would** |

| | | |
|---|---|---|
| **mine?" "You have a mistake. Can you find it? Show me where it is."** If the error is on the back, wait to see if the person can locate the error spontaneously. If you are holding the leather for the person, do not turn it over to show the person the error on the back until the person asks you to do so. | **mistake is right here,"** while pointing to the error. **"I want you to make yours look just like mine."** | **to show you again?"** Take out the error and start the demonstration over. Repeat the demonstration one time. If you think impairments (hand or vision) could explain the person's difficulties, change to the LACLS now. Do not provide a third demonstration with the LACLS |

A whipstitch cross and twist cannot be scored if visual impairments or language comprehension are alternative explanations for being unable to do this part of the screen. Scores of 4-0 to 4.4 can be confounded by these factors. When in doubt, continue the screen by going on to the single cordovan stitch. If the person scores 4.2 or 4.4 on the whipstitch, proceed to the single cordovan stitch. If the person scores 4.0 or lower, stop the screen. When there is a discrepancy between the whipstitch and single cordovan stitch, score the highest score.

# Single Cordovan Stitch:

The task difficulty jumps from an ACL 4.4 demand to an ACL 5.8 demand when the single cordovan is introduced. The jump occurs as an outcome of creating an opportunity to observe learning without a demonstration.

Hand the leather to the person and point to this stitch. **"Can you do this stitch by yourself?"** An immediate response of panic, frustration, or a refusal to try to figure out how to do the stitch is an indication that the problem is too hard for the individual. Offer assistance by asking if the person would like a demonstration. Anytime that the person looks lost, frustrated, or in danger of quitting, offer a demonstration. Only two demonstrations can be scored. Provide verbal and demonstrated directions simultaneously:

**"Would you like to be shown how?"** If so, continue**: "Watch me carefully. Bring the needle to the front of the leather. Push the needle through the next hole towards the back of the leather. Don't pull the lacing tight but leave a small loop in it. Bring the lacing to the front of the leather. This time put the needle through the loop you have made. Keep the needle to the left of the lacing**. (Show the insertion of the needle) **Pull the lacing through the loop towards the back of the leather. Tighten the lacing from the back hole, then tighten the long lacing end. Make sure the lacing isn't twisted. Now you do 3 stitches."**

The administrator's response to the person's comments should be as non-directive as possible. If the person asks if he/she is doing it right, say **"What do you think**?" or

**"Is yours like mine?"** or **"Keep trying**"- If the person says "that's not right", say "**Can you fix it?"** or "**Can you show me what is wrong?"**

When a demonstration has not been provided and after a few minutes of attempting to do the stitch, a verbal cue may be provided: **"Would you like some help?"** If so, give a verbal cue with one piece of information such as "**You have the first part right"** or **"Go from front to back".** If that does not help, try pointing out the error. Allow time for the person to try to figure it out. This is not a timed screen. If the verbal cue does not improve performance, offer a demonstration.

Offer a second demonstration when the same mistake is made over and over again or when no improvement in performance is observed. No more that 2 demonstrations can be scored. A few people may insist on a third demonstration, which may be provided but the third demonstration is not scored.

Make sure that the person does 3 stitches. Some people get lucky and do 2 stitches but have not really learned how to do the stitch.

# Allen' Cognitive Levels Screen Scoring Guidelines, 2000

## Running Stitch

3.0 Grasps leather or pushes it away. May not attempt to grasp the lacing or may grasp the leather lacing when handed to the person and moves leather lacing in a random manner.

3.2 Pushes needle through at least one hole, which can be the wrong location. May skip holes.

3.4 Completes at least 3 running stitches with no more than two demonstrations. Does not skip holes.

## Whipstitch

3.6 Does at least one whipstitch in the correct location; no skipped holes.

3.8 Does not recognize twist, cross errors in back when cued. Does recognize running stitch error, but is unconcerned about error. May continue until out of space. May say, "**Am I done?**"

4.0 Does recognize twists or the cross in back as an error when pointed out. Does not attempt to correct twist or cross errors. Corrects running stitch errors on back when pointed out.

4.2 Corrects twists by redoing the last stitch. Does not untwist while lacing is still in the hole. Corrects errors in cross in back.

4.4 Can untwist at least one whipstitch without pulling it out. Stops after 3 stitches.

# Single Cordovan Stitch

5.8 Completes 3 single cordovan stitches without a demonstration or a verbal cue by examining the sample stitches and using trial and error.

5.6 Completes 3 single cordovan stitches without a demonstration but requires a cue (verbal or pointing to location of error) to do the stitch correctly.

5.4 One (but only one) demonstration is given. Corrects errors in directionality, tangled lacing, or tightening in sequence without a second demonstration by altering actions two or more times.

The following scores are after Second Demonstration is Given:

5.2 Corrects errors in directionality, tangled lacing, or tightening in sequence with a second demonstration. The loops are tightened in sequence; the tension may be a little loose but no other errors remain.

5.0 Corrects errors in directionality, tangled lacing, or tightening in sequence but cannot replicate solutions. A little improvement or alteration occurs with a second demonstration but errors remain.

4.8 Lacing is not tightened in sequence (hole then loop), just pulls on needle, may or may not recognize error. Little to no improvement is noted with first or second demonstration.

4.6 Right/left orientation of lacing and needle are incorrect when going through the loop. Little to no improvement is noted with first or second demonstration.

4.4 Goes from front to back through the hole (like the whipstitch) but inserts needle through loop from the back as if it were one step. (Lacing is under loop but does not wrap around it.) Or, directionality goes front to back through the hole but back to front through the loop or vice versa. Does not benefit from first and second demonstration.

4.2 Repeats the whipstitch or does the whipstitch followed by an attempt to do a second unrelated step. Does not benefit from first and second demonstration.

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## The Routine Task Inventory – 2

The RTI-2 evaluates self-awareness, situational awareness, social roles and occupational roles. Self-awareness includes the activities one does to keep one's body clean, safe, healthy, comfortable and attractive. The universal nature of these activities makes it possible to list the steps required to complete each task. Tasks included are grooming, dressing, exercising, eating, and taking medication. Situational awareness refers to the ability to understand situations of daily living encountered at home or in the community. This includes housekeeping tasks, preparing/obtaining food, tasks related to money use, shopping, doing laundry, traveling, telephoning and how a client adapts to a change in their usual routine. Social role abilities are needed to interact with other people, and consist of the ability to communicate, follow directions, and cooperate with others. Occupational Role tasks relate to performing a major role, such as going to work or to school. This includes following a schedule and the ramifications of changing that schedule. Planning and doing spare time activities, following safety precautions and responding to emergencies are some of the other skills that are included in this area. (Allen, et al., 1992)

## The Kitchen Task Assessment and Environmental Assessments

The Kitchen Task Assessment which was developed as a practical, objective measure of cognitive function demonstrated in a common task (such as making cooked pudding). Originally, the sample population was adults diagnosed with Alzheimer's disease; however, it has been hypothesized that this tool would be useful for clients functioning at higher levels (i.e. borderline mental retardation or learning disability). This tool can help the therapist determine the level of assistance the client may require to perform tasks safely, which can be helpful when making recommendations for supervision in a home environment. An environment assessment can be developed in order to complete a home environment checklist. These checklists typically include an evaluation of the entryway, bedroom, bathroom, kitchen, and other living areas (Pedretti, 1996).

**INTERVENTION PLAN BASED ON ASSESSMENT RESULTS**

**Client Name:**

**DOB:**

**Diagnosis:**

**Etiology:**

**Client Physical/Medical/Disabilities:**

**ACL Level:**

**Grooming**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Dressing**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Medication Management**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Bathing**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Toileting**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Eating**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Housekeeping**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Meal Planning/Preparation**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Money Management**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Shopping**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Laundry**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Transportation**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

**Phone**

Current Performance:

ACL Prediction of Performance:

Staff Assistance Recommendations:

Safety Concerns:

Goal:

Signature date

## Task Analysis Protocol

**The Activity:** Briefly describe the activity, which performance areas of occupation encompass?

**Activity Demand Aspects** (Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy, 56,* p. 624)

***Objects and Their Properties:***

***Space Demands (relates to physical context):***

***Social Demands (relates to social and cultural context):***

***Sequence and Timing:***

(Bass, 2003)

**Staff Training Protocol**

1. Mandatory meeting for all support staff
2. Review client history and personal information (pp.5 and 7)
3. Provide handout on summary of the client's functional level (Based on results of p. 9)
    - Review information in Allen's Cognitive Level Summary (Allen, Earhart, & Blue, 1992) (Appendix I)
        - NOTE: If information in Appendix I is actually utilized in staff training, permission from the authors will need to be granted.
4. Identify problem areas (p. 23)
    - Get staff input and observations
    - Tie in with the ACL predicted performance and client's actual performance
5. Discuss established goals (p. 23)
6. Instruct support staff on teaching the client new tasks based steps defined in the task analysis (p.28)
    - Consistency is crucial when teaching a new task
    - Provide support staff with the completed task analysis
7. Questions

**Appendix I**

## Allen's Cognitive Levels Summary

### Level 1 - Automatic Actions

Individuals functioning at this level of often in hospital beds with the side rails in order to keep them from falling. Unless they are agitated or in pain, they tend to lie still and stare into space. Moaning or crying in response to pain may be heard. It is possible elicit a few responses to external stimuli. These individuals do not perform any activity sitting or standing up because their bodies do not hold them against gravity. When placed in an upright position, be it a bed, a chair, a wheelchair or a bathtub, they tend to slide down and out of it. Positioning devices are available to assist holding them in place to prevent injury. Nearly all grooming activities are required to be completed by a caregiver. The distinction between levels 1 and 2 is that motor responses are elicited by another person or pain in level 1. At level 2, motor actions are self-initiated. (Allen, Earhart, & Blue, 1992, pp. 12-13)

### Level 2 - Postural Actions

When initiating any motor actions the first is to sit upright. This movement requires to push oneself up against gravity in order to keep from sliding down in one's seat. Caution needs to be taken when an individual within this level goes to sit down because they may not look to see if a chair is behind them. Self care activities still require a great deal of assistance from caregivers. These individuals may resist movements the

caregiver wishes them to complete, for example, they may resist standing in the shower or sitting on a toilet. Individuals functioning at a level 2 are usually up and walking around. They tend to slowly wander around aimlessly. Eating can be accomplished if their meal is set up in front of them at a table and utinsels are handed to them. Self-feeding tends to be quite messy and methods of controlling the mess need to be taken by caregivers. While individuals functioning at a level 2 are able to ambulate and complete other gross motor activities but lack the ability reach out to grab objects to maintain stability. The distinction between levels 2 and 3 is that grasp is limited to achieving postural stability. (Allen, et al., 1992, pp. 13)

**Level 3 - Manual Actions**

At this level individuals are able to utilize their hands in order to grasp objects and move them about. This advancement is evident in the ability of the individual to assist with self-care activities such as washing their hands, brushing their teeth and hair, eating with less spilling, etc. When bathing the individuals may get in and out of the shower without assistance and may even use a washcloth independently. Assistance may be required to safely adjust the water temperature, to scrub hard enough to remove soil, to avoid too much pressure in sensitive areas, and to dry all body surfaces. Individuals at this level consistently miss major visual cues such as their shirt on backwards, inside out or out of sequence (i.e.

underwear on top). They require almost constant cueing to complete an activity. At this level persons do not recognize the need for assistance with activities and thus do not ask caregivers for such. They are able to eat food without constant cueing but may require assistance for tasks such as cutting meat. Toileting is increasingly self-initiated. Individuals at this level may recognize the urge to go, get themselves to the bathroom, lower their pants, sit down and void, but they may require cueing to use toilet paper, get up off of the toilet, button and zipper their pants, wash their hands, etc. Walking is a major concern. Individuals may wander off aimlessly and become lost and confused. They may also pick up various objects in their environment and occasionally use them in an inappropriate manner. For example, a young gentleman on his walks often picked up rocks that caught his eye. Staff finally followed him to see what he did with these rocks. They found that he had been placing them in the gas tanks of cars in the parking lot for safe keeping. The use of tools is present at level 3. The distinction between levels 3 and 4 is that the completion of the goal is only recognized after the task is “done” at level 3. During the process of doing the task, someone else must sequence the steps. The sense of completion is internal and may not correspond with social standards for getting the job done. (Allen, et al., 1992, pp.13-14)

**Level 4 - Goal Directed Actions**

Having a goal in mind is a key component in level 4 because the individuals are able to sequence themselves through the steps of an activity in order to get a job done. Most self-care activities can be completed independently with only slight errors of minor details. The individual may look a little odd but the activity was completed independently. Taking medication can be a major self-awareness concern when they get confused about what they are taking and what it does or does not do for them. Refusing to take medications or not recognizing and reporting side effects are common problems for people functioning at a level 4. The disability becomes more apparent in the performance of household activities. Their residence may become messy and dirty and laundry may not be done very often. Their diet may be restricted to a few simple things that require little or no preparation. A daily allowance for spending money is the safest way to manage money. Bills tend to cause problems, often the individual will either forget them or obsess on them. Many individuals functioning at a level 4 are able to live independently in the community. They rely on the consistency of a routine in order to complete all activities. When new situations arise and the person is unable to problem solve and often rely on others to handle trivial matters such as a closet door which won't close properly or a CD which has a scratch on it. The poor quality of performance which the individual is able to get by with at home, isn't as well tolerated in the community. Adults are not able to hold jobs unless

special circumstances are created for them by a vocational counselor. Once a job is set up the individual may be extremely dedicated to the job and work well with the structure and routine of the job itself. Social roles are often strained and learning a new task may take months of repetition before they learn it. The distinction between levels 4 and 5 is that learning is limited to rote learning at level 4. Rote learning is memorizing the steps to complete a new activity without the flexibility to understand, verify and/or change the steps. (Allen, et al., 1992, pp. 14-15)

**Level 5 - Exploratory Actions**

Flexibility to change the steps is present at level 5. The first changes are continuous adjustments in neuromuscular effects, like variations in pressure and strength. Learning occurs through the process of trial and error. All self-care activities are independent at this level and most are done without difficulty. Medications can still be a concern and should be overseen. Household activities are done better than at level 4. Housekeeping is improved because they take notice of more subtle cues from their environment, such as cobwebs, crumbs, hair, and fingerprints. Laundry is done more often because the dirt is seen. Hot meals are prepared, and variation in their diet exists. Shopping, spending money, and talking on the telephone too long are often activities which cause problems. A failure to anticipate events and plan ahead produces many

inconveniences at this level. These activities may include things such as refilling prescriptions, buying stamps, buying birthday cards, making a grocery list and remembering to take it with them to the store, noting the time things expire or when something is done cooking. Participation within major roles in the community can be done successfully with supervision. A key component to successful living at level 5 is maintaining a schedule or calendar of events and obligations. Allen states that the phrase “an accident waiting to happen” may have been invented to describe people functioning at a level 5. They can learn a safety procedure but following it consistently is a problem. They act impulsively without considering the consequences. Learning is based on immediate effects of actions, and secondary effects are not anticipated. The difference between levels 5 and 6 is that planning a future course of action and understanding secondary effects occurs at level 6. (Allen, et al., 1992, pp. 15-16)

**Level 6 - Planned Actions**

Anticipating secondary effects and planning in the absence of material objects occurs at level 6. Therapists observe patients for pauses to stop and think before acting at level 6. Persistence in solving the problems that do occur is expected, but many mistakes are predicted and therefore avoided. Speech includes a discussion of several courses of action. Fine-motor coordination and dexterity are executed with ease while talking, listening, or thinking about something else. At level 6 the system is open to

all of the social, cultural, and historical information available to the person, to be processed as the individual pleases. (Allen, et al., 1992, pp.16-17)

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# CHAPTER 5

## SUMMARY

There are many areas for further expansion and research in regards to occupational therapy services with the developmentally disabled not covered in this scholarly project. These include but are not limited to, research and documentation of the applicability of the ACL to the DD population, comorbidity of mental illness and DD, and the utilization of assistive technology.

Currently, the ACLS is not standardized for the developmentally disabled population. Many occupational therapists have recognized it's potential applicability to this population and research is currently being conducted. Herge and Loving (2002), both MOTS, are actively pursuing the use of Claudia Allen's Cognitive Disability Model with the developmentally disabled population. They have presented a workshop entitled "Piloting the Application of the Cognitive Disability Model in Adult Day Programs for the Developmentally Disabled" at several Occupational Therapy Innovation conferences around the country. Initial research is very promising, but further research is necessary to determine the validity and reliability with this population.

Another area of potential expansion of occupational therapy services with this population is the comorbidity of mental illness with developmental disability. It is estimated that 20% to 35% of all persons with mental retardation also have some form of psychiatric involvement as well. Dr. Robert Fletcher of NADD, an association for persons with developmental disabilities and mental health needs, has suggested that many causes of mental illness have much to do with the

marginalized place persons with mental retardation hold in society compared to the general population. This includes negative social interactions, increased stress, increased feelings of stigmatization and rejection, decreased coping skills, often due to a limited ability to express feelings; and decreased social supports (Fletcher, 2000). This range of needs is conducive to involvement of occupational therapy services with this population.

Individuals with developmental disabilities often have difficulty performing day to day activities without assistance, whether it is from other people or assistive technology. Assistive technology can easily be applied to this population to increase independence with nearly every aspect of their lives. Further evaluation and assessment to determine if assistive technology is appropriate should be completed by the occupational therapist.

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